Cutting the Gordian Knot of Futility: A Case for Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining Treatment

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1. Introduction

In Australia and New Zealand, courts, hospitals, health care professionals, patients, and their families and friends are wrestling with gut-wrenching conflicts that can arise when the health care team believes that treatment should not be provided and the patient's loved ones believe that it should. Occasionally, details of specific cases spill over into the media, engaging the public in the often-heated debate. Talk of 'unrealistic expectations', 'false hope', and 'futility' abounds and tests for defensible withholding or withdrawal of treatment, such as 'a reasonable prospect of returning a patient to a meaningful quality of life' and 'accepted medical practice', are proposed.

In this paper, we will attempt to take a step back from the drama and vitriol and suggest an approach to law and policy reform grounded in identification of core values, careful conceptual analysis, and a dose of humility and pragmatism. To that end, we reflect on the core values that do (or should) underpin a regulatory framework for deciding on whether potentially life-sustaining treatment should be withheld or withdrawn. These values and the ways to balance these values against each other are drawn from legislation, the common law and conventions and treaties that have been ratified by Australia and New Zealand.[1] We then summarise the legal context in Australia and New Zealand within which the ethical debate about the unilateral withholding and withdrawal of potentially life-sustaining treatment is situated; and we undertake a critique of that law as against the core values that we have articulated. Finally, we offer a proposal for how the law might be reformed such that it will more closely align with the core values it is supposed to

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[1] The primary sources that support these values and the balancing are identified and considered in section 2.

serve by shifting the decision-making authority from doctors to patients and substitute decision-makers. These proposals would be suitable for adults with and without decision-making capacity, as well as for children. We hope that in the end this field might move from friction to accord and, ultimately, to better care for both the living and the dying.

We note finally that this paper focuses on the *unilateral* withholding and withdrawal of potentially life-sustaining treatment. This is where a doctor withholds or withdraws treatment without consent from a patient or patient's substitute decision-maker ('sdm')[2] (where the patient lacks capacity), or authorization from a court or tribunal, or by operation of a statute or justifiable government or institutional policy. In other words, where a doctor withholds or withdraws treatment on his or her own authority.

2. Values that govern this area of law

When doctors and patients (or their sdm) disagree on whether treatment should be provided, it is critical to have laws and policies in place that can resolve the impasse. So that all involved can have confidence in the outcome reached, it is important for such laws and policies to be appropriate. Just what the regulatory framework should look like requires a step back to consider the values that are implicated in, and should ground, law and policy with respect to the issue of unilateral withholding and withdrawal of potentially life-sustaining treatment. In our view, these values include life, autonomy, equality, the rule of law, distributive justice, procedural fairness, access to justice, conscience and humility. A detailed examination of each of these values and the balancing of them against each other is not possible in a paper of this length but we note the legal sources for each of them drawing either on the law that governs end of life decision-making or the general principles that underpin our broader legal system. We consider each of these values in turn.

2.1 Life

Our starting point is to acknowledge the fact that the value of human life is recognised by the common law. In *Airedale NHS Trust v Bland*, the House of Lords accepted that 'sanctity of life' formed part of the English legal system[3] and Australian and New Zealand courts have also recognised the State's interest in preserving human life.[4] However, this is not an absolute value. The law in Australia

[2] We use this term as a generic one as there are different titles given in various jurisdictions to individuals who are legally authorised to give or refuse consent to medical treatment on behalf of an individual who is incompetent.

[3] *Airedale NHS Trust v Bland* [1993] AC 789, 859.

[4] In Australia, see for example, *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88, [5]-[16], and more recently a reference by a majority of the Australian High Court in *Patel v The*

and New Zealand (and indeed in many common law jurisdictions throughout the world) also recognises that the value of an individual's life can sometimes be outweighed by the disvalue of their suffering. In other words, a person may decide that life is no longer worth living. For this reason, the law allows a competent individual to refuse treatment, even if that treatment is necessary to preserve life and is recommended by doctors.[5] Where a person has completed a valid advance directive,[6] and, in some cases, where an sdm refuses treatment,[7] the law also allows treatment to be withheld from a person who lacks decision-making capacity.

A defensible approach to the issue of withholding and withdrawal of potentially life-sustaining treatment should therefore recognise the intrinsic value of life, the possibility of instrumental value for life (for the individual and those the individual cares about), but also the fact that other values can outweigh the intrinsic and instrumental value (if any) of life for a particular individual (for example, the value of respecting autonomy, discussed below).

2.2 Autonomy

Queen to 'the value the law places on human life': (2012) 290 ALR 189, [87]. In New Zealand, the value that the law places on human life was recognised in *Auckland Area Health Board v Attorney-General NZ* [1993] 1 NZLR 235, 244-245 in the context of withdrawing treatment. It is also evidenced by comments made by sentencing judges in the criminal law context where the convicted person has unlawfully killed another. See, for example, *R v O* [2012] NZHC 796, [18]; *R v John Tahana Rawiri and Ors* [2009] NZHC 1036, [94]; *R v Crutchley* [2008] NZHC 1078, [65]; *Martin v R* [2005] NZCA 3, [136]; *R v Erstich* [2002] NZCA 122, [26].

[5] See, for example, *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84; *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449; *Auckland Area Health Board v Attorney-General NZ* [1993] 1 NZLR 235, 245; *Smith v Auckland Hospital Board* [1965] NZLR 191, 219.

[6] See generally Lindy Willmott, Ben White and Shih-Ning Then, 'Withholding and Withdrawing Life-Sustaining Medical Treatment' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson Reuters, 2010) [13.100] (the common law), [13.150]-[13.170]; PDG Skegg, 'Justifications for Treatment without Consent' in PDG Skegg and R Paterson (eds), *Medical Law in New Zealand* (Thomson Brookers, 2006) 231, Lindy Willmott, Ben White and Ben Matthews, 'Law, autonomy and advance directives' (2010) 18 *Journal of Law and Medicine* 366, Phillipa J Malpas, 'Advance directives and older people: ethical challenges in the promotion of advance directives in New Zealand' (2011) 37(5) *Journal of Medical Ethics* 285. See also the Health and Disability Commissioner's *Code of Health and Disability Services Consumers' Rights Regulation 1996* (NZ), Right 7(5) which recognises the right of a person to use an advance directive in accordance with the common law. See also *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 which recognised the right of a competent adult to make a binding advance directive.

[7] See generally Lindy Willmott, Ben White and Shih-Ning Then, 'Withholding and Withdrawing Life-Sustaining Medical Treatment' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson Reuters, 2010) [13.180]-[13.230], [13.300]; PDG Skegg, 'Omissions to Prolong Life' in PDG Skegg and R Paterson (eds), *Medical Law in New Zealand* (Thomson Brookers, 2006) 551-552. Although note in New Zealand, pursuant to section 18 of the *Protection of Personal and Property Rights Act 1988* (NZ), a sdm under that Act may not refuse consent to 'any standard medical treatment or procedure intended to save that person's life or to prevent serious damage to that person's health'.

The principle of respect for autonomy is a fundamental part of Australian and New Zealand common law. For example, Gummow, Heydon and Hayne JJ in *Stuart v Kirkland-Veenstra* recognised, in the context of a negligence action, 'an underlying value of the common law which gives primacy to personal autonomy'[8] and observed that personal autonomy is 'a value that informs much of the common law'.[9] There is also Australian authority for this proposition specifically in the end of life setting. For example, in *Brightwater Care Group (Inc) v Rossiter*, Martin CJ refers to the 'common law principle of autonomy and self-determination'[10] and also notes that the principle is 'well established at common law'.[11] In that case, a man with quadriplegia was being kept alive by the delivery of artificial nutrition and hydration through a tube into his stomach. He was not in the terminal phase of an illness and, provided the treatment was given, he would have continued to live. Nevertheless, he decided that he no longer wished to receive such medical treatment and the Western Australian Supreme Court recognised his right to self-determination by declaring that it would be lawful to withdraw the treatment.

In New Zealand, autonomy underpins the ability of a person to refuse medical treatment, a right that is embedded in its Bill of Rights,[12] and is recognised in case law.[13]

We note that the concept of 'autonomy' has many different meanings in law.[14] In the context of refusals of treatment, autonomy has generally been interpreted in Australia and New Zealand as the narrow right to prevent physical interference with one's bodily integrity.[15] This is what requires a refusal of treatment to be respected at law. A wider view, a right to self-determination, involves having one's will

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[8] *Stuart v Kirkland-Veenstra* (2009) 237 CLR 215, [87].

[9] *Stuart v Kirkland-Veenstra* (2009) 237 CLR 215, [88]. See also, for example, *Cole v South Tweed Heads Rugby Club* (2004) 217 CLR 469, [14] (Gleeson CJ); *Perre v Apand Pty Ltd* (1999) 198 CLR 180, [88] (McHugh J).

[10] *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84, [48].

[11] Ibid [24]. For other examples, see *H Ltd v J* (2010) 107 SASR 352, 369 and the heading 'Common law right to self-determination' at 364; and *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88, [5].

[12] *New Zealand Bill of Rights 1990* (NZ), s 11.

[13] See, for example, *Re G* [1997] 2 NZLR 201, 210.

[14] In philosophy, it has even more different meanings. For example, contrast the conception of autonomy articulated by John Stuart Mill (a liberal individualist) in *On Liberty* (Longman, Roberts & Green, 4th ed, 1869) with that articulated by Susan Sherwin (a feminist relational theorist) in 'A Relational Approach to Autonomy in Health Care' in Susan Sherwin (ed), *The Politics of Women's Health: Exploring Agency and Autonomy* (Temple University Press, 1998) 19. However, given that, as explained earlier, we are grounding the values used in the analysis in the values as embraced and understood by the legal system, we do not include a discussion of the full range of possible meanings here.

[15] See, for example, *Secretary, Department of Health and Community Services (NT) v JWB and SMB (Marion's Case)* (1992) 175 CLR 218, 232-233, 265, 309-210; *Hunter and New England Area Health Service v A* [2009] NSWSC 761, [5], [17]; *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84 at [23], [24], [26], [31]-[32]; *Auckland Area Health Board v Attorney-General (NZ)* [1993] 1 NZLR 235, 245; *Airedale NHS Trust v Bland* [1993] AC 789, 826 (Lord Hoffman), 857 (Lord Keith), 864 (Lord Goff).

respected and acted upon and would include the ability to determine that they receive particular treatment.[16] It is this latter view of autonomy that we consider to be the relevant value that should inform a model dealing with decisions to withhold or withdraw potentially life-sustaining treatment.

We see the case for the embrace of this wider sense of autonomy as resting on the central place of autonomy in contemporary society. Autonomy is so entrenched in our society generally and in medical decision-making (particularly end of life decision-making), that to exclude it would be indefensible. If the narrower view of autonomy set out above is taken, the concept of autonomy can play no role in the debate about unilateral withholding and withdrawal. While the narrow view has received firm and unwavering support in law, it is not sufficient here as we are not considering *refusals of treatment*. Therefore it is only if we contemplate a wider view of autonomy that this concept can play a role. Accordingly, we include autonomy as a relevant value for designing a model for decision-making in this area and by this we mean autonomy in the wider sense of having one's will respected and acted upon. That is not to say that a person's right of self-determination should always be determinative; that right is subject to competing claims (which will be considered below).

It must be noted here that the patient will not be competent in most of the cases at issue in this paper. Therefore, insofar as autonomy is a relevant value, we are often dealing with past autonomy as expressed through advance directives and sdms where the sdm is able to represent the patient's wishes or values. For example, an individual may be an Orthodox Jew and believe that one must pursue all possible means to prolong life and so might wish treatment even in the face of a persistent vegetative state. Or an individual may believe that it would be very important for the psychological well-being of her children to be able to say goodbye to her while she is still alive even if she is unconscious, and so she would want ongoing treatment until such time as her children could get to the hospital to say goodbye. An individual might believe that Chinese remedies can cure cancer and want aggressive Western interventions for the window of time it might take for the Chinese remedies to have a chance to be effective. In all of these cases, the doctors and/or the patient's family might not wish for treatment to continue but doing so would be respectful of the patient's past autonomy.

[16] See Loane Skene, 'Disputes about the Withdrawal of Treatment: the Role of the Courts' (2004) 32 *Journal of Law Medicine and Ethics* 701 where she comments on the narrow and wide interpretations of the concept of autonomy in the context of decisions about withholding and withdrawing life-sustaining medical treatment. The wider approach to autonomy was adopted by Justice Munby at first instance in *R (Burke) v General Medical Council* [2005] QB 424, [130] where he commented that article 8 of the *Human Rights Act 1998* means that it is for a competent patient to decide the treatment he or she should or should not be given. Note however Munby J's decision and this more expansive approach to autonomy was overturned by the Court of Appeal: *R (Burke) v General Medical Council* [2006] QB 273.

Given the fundamental commitment to respect for autonomy, a defensible approach to the issue of withholding and withdrawal of potentially life-sustaining treatment should recognise that autonomy is violated where treatment is unilaterally withheld or withdrawn against the wishes of the patient (or sdm), and should only permit such violation where justified by reference to some higher value(s).

2.3 Equality

The legal landscape in Australia and New Zealand demonstrates the commitment of these countries to the value of equality. Over recent decades, Australia and New Zealand have become signatories to various conventions and treaties, including the Convention on the Rights of Persons with Disabilities, which support and promote the value of equality,[17] and have enacted human rights[18] and anti-discrimination legislation.[19] These instruments aim not only to prevent discrimination against people with disabilities, but they also strive to ensure such individuals receive the same standard of health care as the able-bodied. They also prohibit discrimination on the basis of race or culture. Underpinning such instruments is recognition of racial and cultural diversity within our communities, and the need for society to accept and respect diversity.

The value of equality is or can be critical when considering decisions to withhold or withdraw potentially life-sustaining treatment. This is particularly the case where the individual has a significant intellectual or physical impairment. There is a very real risk that the attitudes of those who are able-bodied towards disability will inappropriately colour their perception of what is in the best interests of patients in at least two ways that are contrary to the value of equality. First, they may misjudge the quality of the life of the individual in front of them (the quality as experienced by the individual).[20] The case of Baroness Jane Campbell provides a concerning example of presumptions that can be made by doctors. Baroness Campbell has muscular atrophy and was rushed to the emergency department one evening with severe pneumonia. In her view, doctors were not prepared to treat her until they were shown photos of her receiving her doctoral award.[21] Second, negative

[17] The Convention on the Rights of Persons with Disabilities was signed by Australia on 30 March 2007 and ratified on 17 July 2008, and signed by New Zealand on 30 March 2007 and ratified on 26 September 2008. Pursuant to this Convention, States Parties agree to prohibit all discrimination on the basis of disability (Article 5: Equality and Non-Discrimination) and reaffirm that every human being has the inherent right to life (Article 10: Right to Life).

[18] *New Zealand Bill of Rights Act 1990* (NZ); *Charter of Human Rights and Responsibilities Act 2006* (Vic); *Human Rights Act 2004* (ACT).

[19] See, for example, *Human Rights Act 1993* (NZ); *Disability Discrimination Act 1992* (Cth); *Anti-Discrimination Act 1991* (Qld); *Equal Opportunity Act 1984* (WA); *Anti-Discrimination Act 1977* (NSW); *Equal Opportunity Act 1984* (SA).

[20] This issue is explored by Phillip French and Rosemary Kayess in 'Deadly Currents Beneath Calm Waters: Persons with Disability and the Right to Life in Australia' [2008] *University of New South Wales Faculty of Law Research Series* 34, [4.8].

[21] The text of her address is available at <http://disability-studies.leeds.ac.uk/files/library/Campbell-Withholding-Treatment1-Janes-final-draft-8.11.04.pdf>

conclusions about the quality of life of specific individuals may send a strong message to other individuals with disabilities that their lives are worth less than those of the able-bodied.[22]

There is also a risk that judgments will be made that discriminate on the basis of race or culture. Health care professionals may see beliefs in non-dominant treatments as completely irrational. They may see beliefs about the value of continued life (even in a persistent vegetative state for example) as being unreasonable. This issue arose in the Victorian case of *Re Herrington*[23] in which the family of Ms King, an Aboriginal woman in a persistent vegetative state, disagreed with the health care team's decision to discontinue treatment, including the provision of antibiotics and artificial nutrition. The family's position was grounded in part in Aboriginal beliefs in the provision of food and drink and 'caring for people who are unwell.'[24] After stating that he had 'considered everything said about the cultural values of Aboriginal society by them [the patient's family] and by the social worker',[25] Justice Williams ultimately deferred to the doctors' opinion.[26]

Careful attention must be paid to ensuring cultural competence[27] (or, as it is sometimes known in New Zealand, cultural safety) so as to protect and promote equality with respect to race or culture. This means that decision-makers in the face of conflicts between doctors and patients' families must understand (or be able to come to understand in the context of the proceeding) the relevant cultural components of positions being taken by others. Circling back to disability, they must also understand (or be able to come to understand) the ways in which people who are differently abled than themselves perceive disability. In sum, they must

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Similar concerns were expressed by the New South Wales Ombudsman in New South Wales Ombudsman, *Report of Reviewable Deaths in 2005 Volume 1: Deaths of people with disabilities* (November 2006) <http://www.ombo.nsw.gov.au/__data/assets/pdf_file/0016/5191/ARReviewableDeaths_disability 2005.pdf>. See also Pauline Heslop et al , *Confidential Inquiry into premature deaths of people with learning disabilities* (2013) <http://www.bris.ac.uk/cipold/fullfinalreport.pdf>

[22] Jocelyn Downie and Karen McEwen, 'The Manitoba College of Physicians and Surgeons Position Statement on Withholding and Withdrawal of Life-Sustaining Treatment (2008): Three Problems and a Solution' (2009) 17 *Health Law Journal* 115.

[23] *In the matter of Herrington; Re King* [2007] VSC 151.

[24] *In the matter of Herrington; Re King* [2007] VSC 151, [18].

[25] *In the matter of Herrington; Re King* [2007] VSC 151, [23].

[26] *In the matter of Herrington; Re King* [2007] VSC 151, [24].

[27] For the importance of cultural competency in the delivery of health care generally, see Victorian Department of Health, *Cultural Response Framework* (2009) <http://www.health.vic.gov.au/__data/assets/pdf_file/0008/381068/cultural_responsiveness.pdf>; Sarah Stewart, *Cultural Competence in Health Care* (*Position Paper*, Diversity Health Institute, 2006) <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.110.8602&rep=rep1&type=pdf >; Royal Australasian College of Physicians, 'An Introduction to Cultural Competency' (2006); National Health and Medical Research Council, *Cultural Competency in Health: A guide for policy, partnerships and participation* (Australian Government, 2005) <http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/hp19.pdf>. For the importance of cultural competency in the specific field of end of life, see Katherine Clark and Jane Phillips, 'End of life care: The importance of culture and ethnicity' (2010) 39(4) *Australian Family Physician* 210.

also avoid basing unilateral decisions (inasmuch as they are permitted) on discriminatory beliefs or attitudes and must be alert to patterns of discrimination (including indirect discrimination) in practice and policy.

2.4 Rule of law

A fundamental plank of the legal system in both Australia and New Zealand is adherence to the rule of law.[28] There is no universally accepted definition of the rule of law. However, the Law Council of Australia has identified a number of key principles which, together, articulate its understanding of the rule of law. The first of these principles states that 'the law must be both readily known and available, and certain and clear'.[29]

The current law in this area poses a number of challenges for this aspect of the rule of law. A review of three Australian jurisdictions recently concluded that '[t]he law governing the withholding and withdrawing of life-sustaining treatment from adults who lack capacity is not only complex, it is also at times uncertain, internally inconsistent, inconsistent with good medical and ethical practice, and counterintuitive.'[30] It is *uncertainty* in the law that poses the most serious threat to the rule of law in this area of unilateral withholding and withdrawal of treatment. If, after reasonable investigation and analysis of the law, it is not possible to determine what legal rights and duties arise, then the state of the law offends the rule of law.

But even where the law *is* capable of being determined, if the state of the law makes doing so very difficult, this can also threaten the requirement of the rule of law that the law must be able to be ascertained. This is particularly so in an area of law such as unilateral withholding and withdrawal where it is expected to be used by doctors,

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[28] Lawbook, *The Laws of Australia* (at 16 January 2013) 21 Human Rights, '1 Development and Recognition of Human Rights' [21.1.140]; Peter Bailey, *The Human Rights Enterprise in Australia and Internationally* (LexisNexis Butterworths, 2009) 242-253; Philip A Joseph, *Constitutional and administrative law in New Zealand* (Thomson Reuters, 2007) 196-198; Justice John Toohey AC, 'A government of laws, and not of men?' (1993) 4 *Public Law Review* 158, 168-169. See also *Patel v Chief Executive of Department of Labour* [1997] 1 NZLR 102, 110-111; *Australian Communist Party v The Commonwealth* (1951) 83 CLR 1, 60-61.

[29] Policy Statement, Law Council of Australia, 'Rule of Law Principles', 2: <http://www1.lawcouncil.asn.au/lawcouncil/images/LCA-PDF/a-z-docs/PolicyStatementRuleofLaw.pdf> See also Esther Majambere, 'Clarity, precision and unambiguity: aspects for effective legislative drafting' (2011) 37(3) *Commonwealth Law Bulletin* 417, 418-419, 425; The Hon J J Spigelman AC, 'Access to Justice and Access to Lawyers' (2007) 29(2) *Australian Bar Review* 136, 143; Margaret Jane Radin, 'Reconsidering the Rule of Law' (1989) 69(4) *Boston University Law Review* 781, 786.

[30] Lindy Willmott et al , 'The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 3 (Victoria)' (2011) 18 *Journal of Law and Medicine* 773, 794. See also Ben White et al, 'The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 1 (New South Wales)' (2011) 18 *Journal of Law and Medicine* 497; Lindy Willmott et al, 'The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 2 (Queensland)' (2011) 18 *Journal of Law and Medicine* 522.

other health professionals, patients, families and carers, and the wider community without recourse to legal advice.

Another challenge to understanding the law relates to the *complexity* of the law in this area. The more complex the legal principle, the greater the chance that the law will not be understood by those who are subject to it. The authors acknowledge there are likely to be intractable complexities in applying law on withholding and withdrawing treatment. For example, there is a need to regulate various situations such as whether a patient has capacity or not. But other complexity arises from regulation in this area being spread over both common law and statute (and sometimes more than one statute).

A further challenge is *inconsistency*. This is related to complexity in that inconsistent regulation can be complex but it poses additional problems in that it requires the followers of law to know that similar situations are not treated in a similar way by the law. In our context, the decision-maker and criteria for decision-making in one instance should be the same in an equivalent instance. For example, we consider it makes no sense for doctors to have powers of unilateral withdrawal or withholding if a person has capacity to make decisions about their own health care, but not have that power once the person loses decision-making capacity.[31]

A final challenge to understanding the law in this area is that the meaning of key concepts is *not transparent*. Conceptual slipperiness, particularly in relation to terms which are key legal triggers, undermines the rule of law requirement that the law is ascertainable. In section 4 below, we consider how the law's treatment of the pivotal terms 'futile' and 'necessaries of life' undermine people's ability to know and apply the law.

Given the significance of the rule of law to the Australian and New Zealand legal systems, and the current challenges posed to it by existing regulation of decisions to withhold or withdraw potentially life-sustaining treatment, this is an important value that must drive the project of law reform.

2.5 Distributive Justice

Another consideration that can be significant in cases involving withholding and withdrawal of potentially life-sustaining treatment is the fact that resources are finite. Resources of all descriptions including intensive care unit beds, dialysis units, organs for transplant are in limited supply, and there will be times when giving or continuing treatment for one patient means that one or more others do not get treatment. In addition, a dollar spent on health care may mean one less dollar spent

[31] See section 3 (including section 3.1) below where the law is described. For more detail, see Lindy Willmott, Ben White and Jocelyn Downie, 'Withholding and withdrawal of 'futile' life-sustaining treatment: Unilateral medical decision-making in Australia and New Zealand' (2013) 20 *Journal of Law and Medicine* 907.

on other forms of social services. We should not, however, hide from this fact. It is not immoral to ration resources. It happens frequently and it is necessary: no country can afford to provide all that is medically possible to everyone.[32] But this means doctors should be transparent and not mask issues relating to scarcity of resources behind the cloak of futility.

That said, the allocation must be done in a manner consistent with the principles of distributive justice. Within the broader context of our legal regime, Mullender has observed that 'the law is … an institution that distributes a range of valuable goods and burdens across society'.[33] Smith has considered the meaning of 'distributive justice' in the narrower context of health care, and notes that 'so long as restrictive levels of use for health resources exist, some principle of "maximum societal benefit" must be set'.[34] He advocates for drafting policies based on the principles of distributive justice.[35]

If just policies are in place, then it can be ethically defensible to deny treatment to some individuals. This includes patients who want and request the treatment and even those for whom that treatment would be in their best interests. The manner in which policies on rationing should be drafted to ensure distributive justice is considered next.

2.6 Procedural fairness

If we accept that there needs to be rationing of health care, we must engage in legitimate processes for designing resource allocation policies.[36] The policies must be drafted in an open and transparent fashion with input from individuals and groups with the necessary expertise (with a broad understanding of expertise, including experiential knowledge). Particularly careful attention should be paid to include the perspectives of the very individuals who are most likely to be denied treatment on the basis of the policies. Furthermore, given the commitment to the value of equality discussed earlier, any resource allocation policies which authorise

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[32] See generally Leonard M Fleck, 'Just Caring: Health Care Rationing, Terminal Illness and the Medically Least Well Off' (2011) 39 *Journal of Law, Medicine and Ethics* 156, 157-161.
[33] Richard Mullender, 'Negligence, the Personal Equation of Defendants and Distributive Justice' (2000) 8 *Tort Law Review* 211, 227.
[34] George P Smith II, 'Distributive Justice and the New Medicine' (Edward Elgar Publishing, 2008) 17.
[35] George P Smith II, 'Variables in health care policy-making: Resolving a quandary?' (2009) 17 *Journal of Law and Medicine* 52, 57.
[36] One model based on 'democratic deliberation' has been suggested by Leonard M Fleck, 'Just Caring: Health Care Rationing, Terminal Illness, and the Medically Least Well Off' (2011) 39 *Journal of Law, Medicine and Ethics* 156. See also Jocelyn Downie and Jennifer J Llewellyn, *Being Relational: Reflections on Relational Theory and Health Law* (UBC Press, 2011), especially chapters 2, 3, 8, and 9 for discussions of relational conceptions of justice and judgment and the application of these conceptions to legitimate health policy decision-making processes. See also Norman Daniels and James E Sabin, *Setting Limits Fairly: Learning to Share Resources for Health* (Oxford University Press, 2nd ed, 2008) for a discussion of their "accountability for reasonableness" theory of procedural justice.

doctors to withhold or withdraw potentially life-sustaining treatment must be subjected to rigorous equality analysis prior to approval. Further, once these policies are established, they must be challengeable in the courts or other adjudicative bodies (for example, for being discriminatory) and there must be regulation of the process.

When considering individual decisions about withholding or withdrawing treatment, a procedurally fair decision-making process is particularly relevant and important because of the benefits that come from adherence to the 'hearing rule'.[37] Broadly, the hearing rule requires that a person has adequate notice of a decision that is proposed to be made, access to relevant information and sufficient time to consider it, and an opportunity to participate in the decision-making process and be heard.[38] Procedurally fair decision-making is important because it increases the quality of decision-making. When all relevant information is shared and discussed, this ensures that views, assumptions and conclusions can be rigorously tested.[39] An opportunity to participate in decision-making can also lead to greater confidence and trust in the decision that is made[40] as well as a greater sense of legitimacy for the final outcome.

A legal framework dealing with decision-making about medical treatment at the end of life should promote the achievement of these outcomes. This would mean that decisions about not treating should not, at a minimum, occur in isolation or in secret. The value of procedurally fair decision-making requires frank engagement with the patient or his or her sdm, and the patient (or sdm) would be part of the properly informed decision-making process about whether treatment should be stopped. The importance of the treating team consulting with the patient (or the patient's family) in decision-making about whether to withhold or withdraw treatment has been widely recognised in academic commentary[41] as well as by the judiciary.[42]

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[37] The second element of procedural fairness is that the decision-maker is impartial or free from bias in his or her decision-making. This aspect of procedurally fair decision-making is also important, but it is better dealt with in the context of this paper under the value of 'Equality' considered above.

[38] Robin Creyke,John McMillan and Mark Smyth, *Control of Government Action: Text, Cases and Commentary* (LexisNexis Butterworths, 3 ed, 2012), [10.4.7].

[39] DJ Galligan, *Discretionary Powers: A Legal Study of Official Discretion* (Clarendon Press, 1986) 328; Geoffrey A Flick, *Natural Justice: Principles and Practical Application* (Butterworths, 2nd ed, 1984) 69-70. See also *Re Pochi and Minister for Immigration and Ethnic Affairs* (1979) 26 ALR 247, 274 (Brennan J).

[40] E Allen Lind and Tom R Tyler, *The Social Psychology of Procedural Justice* (Plenum Press, 1988) 63–4.

[41] See, for example, Donna Casey and Thaddeus Pope, 'Resolving Medical Futility Disputes' (2011) 36 *DNA Reporter* 5; Cameron Stewart, 'Futility determination as a process: Problems with medical sovereignty, legal issues and the strengths and weakness of the procedural approach' (2011) 8 *Bioethical Inquiry* 155; Thaddeus M Pope and Ellen A Waldman, 'Mediation at the end of life: getting beyond the limits of the talking cure' (2007) 23 *Ohio State Journal on Dispute Resolution* 143; Thaddeus M Pope, 'Medical futility statutes: No safe harbor to unilaterally refuse life-sustaining treatment' (2007) 75 *Tennessee Law Review* 1. See also Joceyln Downie and Karen McEwen, 'The Manitoba College of Physicians and Surgeons Position Statement on Withholding and Withdrawal of

2.7 Access to justice

Access to justice is an increasing problem in Australia and New Zealand.[43] The rule of law has been identified as a key value in our legal system, but this depends on individuals having access to justice when they feel their legal rights (or those of a loved one) have been infringed.[44] Taking a matter to court is daunting and financially prohibitive for most members of the community. Delays in obtaining redress will sometimes mean that legal recourse is not a practical solution.

These systemic potential barriers to justice can arise when a patient or, more commonly, an sdm, wishes to challenge a doctor's decision to stop potentially life-sustaining treatment. Lawyers and medical experts can be prohibitively expensive, putting the challenging of a doctor's decision beyond the reach of some if not many or, indeed, most. Power imbalances between doctors and hospitals on the one hand and lay persons on the other also reduce the willingness or ability of some to go to court to fight for what they believe to be in the best interests of their loved ones.

Furthermore, just as the resources of the patients and their families are limited (as noted above) and the resources of the health care system are limited (as noted in the discussion of distributive justice earlier), so too are the resources of the legal system. There are not enough lawyers who understand the complexities of end of life law and policy and the court system is severely strained to deal just with what is already before it. One should not establish a process that is too resource-intensive for the system to bear. It would not be practical, for example, to require that all decisions to stop treatment (whether with consent or not) be reviewed by a judge or tribunal. That said, it is also very important to be pragmatic about how many cases would actually not be able to be resolved through effective communication strategies and conflict resolution mechanisms. We predict that it would be a very

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Life-Sustaining Treatment (2008): Three Problems and a Solution' (2009) 17 *Health Law Journal* 115 where the authors proposed not only that the patient or family be consulted, but that continuing treatment should be provided at the request of the patient or sdm in the absence of a resource allocation policy or court order.

[42] See, for example, *Shortland v Northland Health Ltd* [1998] 1 NZLR 433, 443 where the Court of Appeal observed the need for there to be 'reasonable consultation with the patient and such members of the family as are available'.

[43] Geoff Mulherin and Christine Coumarelos, 'Access to Justice and Disadvantaged Communities' in Pascoe Pleasence, Alexy Buck and Nigel J Balmer (eds) *Transforming Lives: Law and Social Process* (Stationery Office, 2007) 9. For comment on the effects of costs on access to justice, see also K McEvoy, 'Access to Justice' (2005) 17(4) *Legal Date* 1; The Hon JJ Spigelman AC, 'Access to Justice and Access to Lawyers' (2007) 29(2) *Australian Bar Review* 136; The Hon Murray Gleeson AC, 'The purpose of litigation' (2009) 83 *Australian Law Journal* 61.

[44] The Honourable Sir Anthony Mason AC KBE, 'PILCH: Access to Justice and the Rule of Law' (Speech delivered at the PILCH (Public Interest Law Clearing House) 10th Anniversary Dinner, Parliament House, Melbourne, 9 September 2004) <http://www.vicbar.com.au/GetFile.ashx?file=VicBarNewsFiles/130PILCH.pdf>.

small number.[45] Doctors who wish to treat a patient against the patient's family's wishes must, in most cases, go to court or tribunal for consent and this is not seen to overwhelm the system. There is no reason to suppose that the numbers would be higher for demands than for refusals. That said, the system should be designed to be as quick, effective, and efficient as it can be while serving the values outlined in this section.[46]

Statutes can create rules, structures, and systems that reduce the need to go to court by creating efficient and accessible ways of resolving disputes. One principle of access to justice is that law should provide a framework for dispute resolution that reduces the need for judicial intervention. This is an efficiency point in that requiring judicial intervention in every case is impractical in terms of time, cost, and scarce legal system resources. It is also an access to justice issue as individuals are unlikely to be able to contest in court as effectively as well-resourced health institutions. There is also evidence that points to the value of avoiding the stress of litigation and the harm it can cause patients and their families.[47]

Nevertheless, intractable disputes will arise under any proposed model. When this does occur, the value of access to justice suggests that there should be efficient and accessible mechanisms, such as tribunals to assist with resolving the deadlock.[48]

2.8 Conscience

An individual's freedom of conscience is recognised both in Australia and New Zealand.[49] The value of conscience can be implicated in cases of conflict over

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[45] Recently, some work has been undertaken in New South Wales to assist in resolving conflicts that arise in end of life settings. In its final Report, 'Conflict Resolution in End of Life Settings' (CRELS) Report 2010, the working party observed as follows: 'The Courts and tribunals will always be needed to resolve a very small proportion of intractable EOL conflict. This is however, a rare occurrence, especially when considered in relation to the level of activity around end of life decisions in the NSW public health system. While it is difficult to estimate accurately, there are probably hundreds of EOL decisions made every day across care settings in NSW.'

[46] The trend in Australia has been the establishment of tribunals which provide quicker and cheaper access to justice than occurs under the judicial system. This can be seen from the objectives of the legislation establishing tribunals: see, for example, *Queensland Civil and Administrative Tribunal Act 2009* (Qld), s 3(b); *State Administrative Tribunal Act 2009* (WA), s 9; *ACT Civil and Administrative Tribunal Act 2008* (ACT), s 6; *Guardianship Act 1987* (NSW), s 55.

[47] Nicole M Zapzalka, *The psychological impact of civil litigation: A comparison of perceived anxiety levels in civil litigation as viewed by trial and alternative dispute resolution litigants* (Capella University, 2007) 74-75; Larry H. Strasburger, MD, 'The Litigant-Patient: Mental Health Consequences of civil litigation' (1999) 27 *Journal of the American Academy of Psychiatry and the Law* 203.

[48] To a large extent, this already occurs in the various Australian jurisdictions. See note 46 above and accompanying text. See also New South Wales, CRELS Project Working Group, *Conflict Resolution in End of Life Settings (CRELS) Final Report* (2010) 5. It is not yet occurring in New Zealand where cases are dealt with in the Family Court or the High Court.

[49] *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 art 18 (signed by Australia on 18 December 1972 and ratified on 13 August 1980, and

withholding and withdrawal. The health care professional may feel that ongoing treatment is not only not in the patient's best interests but to provide the treatment would run counter to the health care professional's conscience. The provision of treatment that the doctor considers to be futile, thereby depriving another patient or patients those health resources, may also be contrary to that person's conscience.[50] To compel the health care professional to provide treatment would be a violation of that person's freedom of conscience.

However, the request of a patient (or the patient's sdm) for treatment may be motivated by their conscience (hence calling for the weighing of one person's conscience against another's) or may be an expression of their autonomy (hence calling for the weighing of one person's conscience against another's autonomy). We would argue that, insofar as it is possible to meet the request for treatment without violating the health care professional's conscience (e.g., by transferring the patient to another health care professional), this should be permitted, indeed facilitated, in the system. Beyond that, in the face of a refusal of consent to the withholding or withdrawal of potentially life-sustaining treatment by the patient or patient's sdm, unless authorised to withhold or withdraw by a court, the doctor should be compelled, even over a conscience claim, to provide treatment. It should also be remembered that, in this kind of case, the patient is already in a therapeutic relationship with the doctor and, unless a referral to another health care professional is possible, it would be contrary to professional ethics for the doctor to cease treating the patient or to treat the patient in a way that is contrary to stated wishes.[51]

This approach to a doctor's conscience (i.e., overriding it in some circumstances when the value of respecting it is overridden by the harms of doing so), is consistent with the law's approach to compelling the cessation of treatment (even where that requires action by the doctor as in the case of removing ventilatory support or transferring the patient to a doctor who is prepared to do so).[52]

2.9 Humility

Humility arises in the context of considering who has privileged access to what information and who can best judge the various elements in the decision to withhold or withdraw treatment. Advocates of unilateral withholding and

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signed by New Zealand on 12 November 1968 and ratified on 28 December 1978); *New Zealand Bill of Rights Act 1990* (NZ), s 13; *Charter of Human Rights and Responsibilities Act 2006* (Vic), s 14; *Human Rights Act 2004* (ACT), s 14.

[50] In Danny Sullivan, 'The moral costs of health care' (1999) 7 *Journal of Law and Medicine* 156, Sullivan argues that a health professional may be justified in refusing to offer treatment on the basis of his or her conscientious objection to using the resources.

[51] See, for example, the Australian Medical Association, *Code of Ethics* (20 November 2006), 16, 18, <https://ama.com.au/codeofethics>; New Zealand Medical Association, *Code of Ethics for the New Zealand Medical Profession,* 6, 13, <http://www.nzma.org.nz/sites/all/files/Code_of_Ethics.pdf>.

[52] *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449, 475.

withdrawal cast doctors as having the requisite knowledge for determinations of 'appropriate treatment' and 'best interests'. Opponents argue that patients themselves or patients' families are better situated to judge what is in the patient's best interests or, where there is reason to doubt the judgment of the patient's families, that judges and tribunals are best situated to make the substituted judgment.

There is a need for doctors to be humble. Doctors must realise that when the decision is at least partly an ethical one (namely, whether the treatment is in the patient's best interests, or is 'worth doing'), they do not have privileged access to the truth. They have relevant information and their opinions, while potentially illuminating, should not be determinative.[53]

This should drive doctors to support a model which recognises that others have greater expertise than they do in relation to what specific patients want or what is in their patients' best interests and, reflecting that, establishes others as the appropriate decision-makers. Such decision-makers may be a patient's legally authorised sdm, court, tribunal, or policy-makers. Such a model would require doctors to obtain consent from the patient or the patient's legally authorised sdm, or authorization from a court or tribunal where the treatment decision rests on whether the treatment is in the patient's best interests (whether seen through a straight best interests approach or through a futility lens).

Tribunals, comprised of individuals with a range of expertise (including with respect to clinical matters as well as disability, culture, and ethics) are arguably better situated than doctors to review the complex medical, moral and social aspects of the decisions at issue in this paper. This conclusion is perhaps reflected in the fact that, in Australia, such matters are increasingly being dealt with by tribunals.[54] Society needs to have a trusted agent to weigh all of the evidence and make the best judgment they can as between the competing positions and it has given that job to judges and tribunal members.

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[53] See, for example, S Moratti, 'The development of "medical futility": towards a procedural approach based on the role of the medical profession' (2009) 35 *Journal of Medical Ethics* 369, 369 where the author observes that futility judgments are based on subjective evaluations of quality of life.

[54] See, for example, the following end-of-life matters that have been determined by tribunals in New South Wales, Queensland and Victoria: New South Wales - *WK v Public Guardian (No 2)* [2006] NSWADT 121; *BAH* [2007] NSWGT 1 (this decision was previously known as *Re AG* [2007] NSWGT 1); *FI v Public Guardian* [2008] NSWADT 263; *LE and LF v Public Guardian* [2009] NSWADT 78; QAN [2008] NSWGT 19; *HH v HI and Protective Commissioner* [2009] NSW ADTAP 41; Queensland - Re AAC [2009] QGAAT 27**;** *Re SAJ* [2007] QGAAT 62**;** *Re MHE* [2006] QGAAT 9**;** *Re HG* [2006] QGAAT 26**;** *Re L* [2005] QGAAT 13**;** *Re MC* [2003] QGAAT 13**;** *Re TM* [2002] QGAAT 1*; Re RWG* [2000] QGAAT 2*; Re PVM* [2000] QGAAT 1; Victoria - *BK (Guardianship)* [2007] VCAT 332; *Korp (Guardianship)* [2005] VCAT 779; *AV (Guardianship)* [2005] VCAT 2519; *EK (Guardianship)* [2005] VCAT 2520; *Public Advocate v RCS (Guardianship)* [2004] VCAT 1880.

However, they too must be humble. The need for humility on the part of courts and tribunals has been recognised by a court. In a 2007 Canadian case,[55] doctors and parents of an eight month old baby in a vegetative state disagreed about treatment. The doctors wanted assisted ventilation withdrawn and the parents did not. The matter came before a Consent and Capacity Board to resolve the impasse. The mother asked two questions of the Panel: what authority the panel had to make the decision; and why the Panel thought it was better placed than she was to do so. The Panel responded:

> The answer to the first question was simple: s 37 of the [*Health Care Consent Act*] authorized Dr Choong's application to the Board and required us to adjudicate. That was our authority. The answer to the second question was rather more difficult, in part because, given the nature of the treatment decision to be made, the question and the decision humbled us.[56]

3. Overview of the law

It is not the purpose of this paper to provide an exhaustive description of the Australian and New Zealand law about a doctor's obligation to provide medical treatment. Such an analysis has been undertaken elsewhere.[57] However, in order to critically review the regime, both in terms of a legal critique and as against the core values we argue should underpin a legal regime, a brief description of the law is necessary here.

When it comes to the provision of medical treatment, obligations are imposed on doctors by both the criminal and civil law regimes. The criminal law imposes a duty upon a person (in this context, a doctor) who voluntarily assumes responsibility for another who is unable to care for themselves due to mental or physical incapacity.[58] In such a case, the doctor has a duty to provide the other with the necessaries of life.[59] Necessaries of life can include medical treatment,[60] so criminal sanction could potentially attach to not providing treatment.

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[55] *In the Matter of EJG* (2007) CanLII 44704 (ON CCB).
[56] *In the Matter of EJG* (2007) CanLII 44704 (ON CCB), 18-19.
[57] Lindy Willmott, Ben White and Jocelyn Downie, 'Withholding and withdrawal of 'futile' life-sustaining treatment: Unilateral medical decision-making in Australia and New Zealand' (2013) 20 *Journal of Law and Medicine* 907.
[58] The Supreme Court of Western Australia explored the extent to which a person would have the 'care and charge of a person', the words used in the WA *Criminal Code*, in *Brightwater Care Group v Rossiter* (2009) 40 WAR 84. That case involved a competent man with quadriplegia who wished to stop receiving artificial hydration and nutrition. In the context of this case, the Supreme Court held that the care facility could not be regarded as having the 'care and charge' of the man. This aspect of the duty is discussed in more detail in Ben White, Lindy Willmott and John Allen, 'Withholding and Withdrawing Life-Sustaining Treatment: Criminal Responsibility for Established Medical Practice?' (2010) 17 *Journal of Law and Medicine* 849.
[59] This duty arises both in the common law jurisdictions (Australian Capital Territory, New South Wales, South Australia and Victoria): *R v Taktak* (1988) 14 NSWLR 226; and the Criminal Code jurisdictions (Northern Territory, Queensland, Tasmania and Western Australia): Northern

The civil law also imposes a duty on doctors to use reasonable care and skill when making treatment decisions in relation to patients.[61] This arises in Australia from the general law of negligence[62] and in New Zealand principally from the *Code of Health and Disability Services Consumers' Rights*.[63] Where medical treatment is needed to keep a patient alive, reasonable care will often dictate the provision of treatment. Withholding or withdrawing potentially life-sustaining treatment can give rise to a breach of this civil duty if doing so falls short of exercising reasonable care and skill.[64]

The assessment of medical treatment as futile in a given case will alter the criminal and civil law obligations just mentioned. The courts have consistently held that, where treatment is assessed to be futile, a doctor is not under a duty to provide the medical treatment. There have been two bases for arriving at this conclusion.

The first is that futile treatment will be treatment that is not in the patient's best interests. Accordingly, if the court agrees with a doctor's assessment of futility, it will not interfere with the doctor's treatment of the patient by requiring that the treatment be provided.[65]

Territory: *Criminal Code* (NT), s 149; Queensland: *Criminal Code* (Qld), s 285; Tasmania: *Criminal Code* (Tas), s 144; and Western Australia: (*Criminal Code* (WA), s 262. An equivalent duty arises in relation to children: in relation to common law jurisdictions, see *R v Russell* [1933] VLR 59 and *R v Clarke* [1959] VR 645 and in the Code jurisdictions, the duty applies to children who are under 16: Northern Territory: *Criminal Code* (NT), s 149; Queensland: *Criminal Code* (Qld), s 286(1)(a); Tasmania: *Criminal Code* (Tas), s 145; and Western Australia: *Criminal Code* (WA), s 263. The duty to provide the necessaries of life in New Zealand is contained in the *Crimes Act 1961* (NZ), ss 151 (general duty), 152 (child under 16 years).

[60] *R v Macdonald and Macdonald* [1904] St R Qd 151; *R v Nielsen* [2001] QCA 85, [3] (Williams JA).

[61] In addition to this civil duty (discussed next), another possible source of legal duty could arise from human rights obligations. To date, however, such obligations have not been influential in the development of the law in this field in Australia and New Zealand: for more detail, see Lindy Willmott, Ben White and Jocelyn Downie, 'Withholding and withdrawal of 'futile' life-sustaining treatment: Unilateral medical decision-making in Australia and New Zealand' (2013) 20 *Journal of Law and Medicine* 907.

[62] *Rogers v Whitaker* (1992) 175 CLR 479 (although note the various civil liability legislation which has altered the common law).

[63] Right 4. See J Manning, 'The Required Standard of Care for Treatment' in PGD Skegg and R Paterson (ed), *Medical Law in New Zealand* (Thomson Brookers, 2006) 61, 61-66.

[64] Compare *Hunter Area Health Service v Marchlewski* (2000) 51 NSWLR 268 which considered the duty of care owed to the parents of an infant who was ultimately the subject of a non-treatment decision. See also *D Lane v Northern NSW Local Health District; E Lane v Northern NSW Local Health District* [2013] NSWDC 12.

[65] A challenge by a family of a doctor's assessment of futility will generally be heard by a court in its *parens patriae* jurisdiction. Such a challenge was made by the family, unsuccessfully, in *Messiha v South East Health* [2004] NSWSC 1061. Compare *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549 where, on an application brought by the patient's sister, the Supreme Court of New South Wales held that the doctor had wrongly withheld treatment that was appropriate and reasonable. In a similar vein, in *Australian Capital Territory v JT* (2009) 4 ACTLR 68, the Australian Capital Territory which ran a care facility in which the patient resided, applied for a declaration that

The second basis is that stopping (or not providing) futile treatment will not constitute a breach of the criminal law duty to provide necessaries of life. There have been two grounds for reaching this conclusion. The first is that if medical treatment is futile, it could not be regarded as a necessary of life. In a decision by the New Zealand High Court, *Auckland Area Health Board v Attorney General,*[66] Thomas J concluded that treatment was a necessary of life if 'required to prevent, cure, or alleviate a disease that endangers the health or life of a patient'.[67] In that case, the patient had severe Guillain-Barre syndrome and there was no prospect of him improving. In these circumstances, Thomas J found that the artificial ventilation that was needed to keep the patient alive was not a necessary of life.

The other ground for escaping criminal sanction was suggested by the New Zealand High Court in the same case. The Court concluded that even if the provision of artificial ventilation was a necessary of life, contrary to the Court's finding, there was a 'lawful excuse' for not providing the treatment. The lawful excuse arose because it was considered to be 'good medical practice' not to provide medical treatment in the circumstances of this patient.[68] In the later decision of *Shortland v Northland Health Ltd*,[69] the New Zealand Court of Appeal further considered the content of the excuse of 'good medical practice'. The patient here was a 63-year-old man with a long history of type II diabetes, end-stage chronic renal failure and dementia. His family had challenged a decision to not allow him into the renal dialysis program.

The Court of Appeal held that not providing the treatment the family sought was not a breach of Northland Health's duty to provide necessaries of life because it was done in accordance with 'good medical practice'. Of significance for our purposes is the court's consideration of one of the elements of 'good medical practice' that was set out in *Auckland*: 'the fully-informed consent of the patient's family'.[70] Although seen as a required part of good medical practice in *Auckland*, the Court of Appeal in *Shortland* explicitly rejected, as a general proposition, the need to obtain the fully informed consent of the patient's family, saying only that the 'appropriate course is to expect, where circumstances permit, that there will be reasonable consultation with the patient and such members of the family as are available.'[71] The Court of Appeal did acknowledge in dicta, however, that 'the criterion may have been

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it would be lawful to not administer artificial nutrition and hydration to the patient. This application was refused as the treatment was not futile in the circumstances.

[66] [1993] 1 NZLR 235, 249.

[67] *Auckland Area Health Board v Attorney General* [1993] 1 NZLR 235, 249.

[68] *Auckland Area Health Board v Attorney General* [1993] 1 NZLR 235, 250-253.

[69] [1998] 1 NZLR 433. For a critique of this case on another ground, namely the failure of the Court of Appeal to engage with whether a decision could be challenged based on the allocation of scarce resources between patients in addition to clinical factors, see Joanna Manning and Ron Paterson, '"Prioritization": Rationing Health Care in New Zealand' (2005) 33 *Journal of Law, Medicine and Ethics* 681.

[70] *Shortland v Northland Health Ltd* [1998] 1 NZLR 433, 442.

[71] *Shortland v Northland Health Ltd* [1998] 1 NZLR 433, 443.

appropriate in the context of the proposed removal of a life-support system, as in the *Auckland* case.'[72]

In summary, the following general observations can be made about the law in Australia and New Zealand regarding a doctor's obligation to provide treatment that is assessed to be futile:[73]

1. There is no general duty on doctors to provide treatment that they consider to be futile.[74]
2. In Australia, doctors do not need consent from the patient or his or her sdm, or other authorization, to withhold or withdraw treatment that they consider to be futile.
3. In New Zealand, doctors do not need consent from the patient or his or her sdm, or other authorization, to *withhold* treatment that they consider to be futile. It is unclear whether consent or other authorization is needed to *withdraw* treatment already being provided.
4. In practical terms, determination of futility is in the first instance made by doctors, but can be challenged by a patient or his or her sdm.

3.1 Statutory modification of the law on futility in Queensland

In Queensland, the law described above has been modified by legislation if the patient is an adult who lacks decision-making capacity. In that jurisdiction, the guardianship legislation requires consent to be obtained from a sdm (or some other authority) before a doctor can withhold or withdraw futile treatment.[75] Therefore, doctors are not permitted to unilaterally withdraw or withhold medical treatment without consent for treatment they assess to be futile. There has been a suggestion

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[72] *Shortland v Northland Health Ltd* [1998] 1 NZLR 433, 443.

[73] This conclusion draws on the analysis of Lindy Willmott, Ben White and Jocelyn Downie, 'Withholding and withdrawal of 'futile' life-sustaining treatment: Unilateral medical decision-making in Australia and New Zealand' (2013) 20 *Journal of Law and Medicine* 907.

[74] While the cases that have considered this issue in Australia and New Zealand relate to incompetent patients, a similar approach is likely to be taken for competent patients: see *R (on the application of Burke) v The General Medical Council* [2006] QB 273, 301-302 where the English Court of Appeal concluded that patients could not demand treatment if the doctors formed the view that it was 'not clinically indicated'.

[75] Section 79 of the *Guardianship and Administration Act 2000* (GAA) makes it an offence for a health provider to carry out 'health care' for an adult with impaired capacity unless the appropriate consent (or some other authorisation) is obtained. 'Health care' is defined in Schedule 2, s 5(2) to include withholding and withdrawal of a life-sustaining measure *if the commencement or continuation of the measure would be inconsistent with good medical practice.* This means that a potentially life-sustaining measure that is considered futile would fall within that definition. For more detail on the Queensland legislation in this field, see Ben White and Lindy Willmott, *Rethinking Life-Sustaining Measures: Questions for Queensland* (QUT Printing Services, Brisbane, 2005) 69-72, <http://eprints.qut.edu.au/7093/>; Lindy Willmott, Ben White and Shih-Ning Then, 'Withholding and Withdrawing Life-Sustaining Medical Treatment' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson Reuters, 2010) [13.240].

that legislation in South Australia and Western Australia has a similar effect[76] but for reasons explained elsewhere, we believe this is not the case.[77]

4. Critique of the current law in light of the core values

Against this backdrop of core values and balancing of values and a description of the current law, we now turn to an assessment of the way in which the issue of unilateral withholding and withdrawal of potentially life-sustaining treatment has been dealt with under Australian and New Zealand law.

Before we commence the critique of the current law in light of the core values, we note that there are some values that the current law promotes. The first is the value of life (value 2.1). The duty to provide treatment that is in the patient's best interests, and the requirement to provide a person with the necessaries of life underscores the value that the law places on life. Nevertheless, the common law world also recognises that the value of life is not absolute. The law recognises the right of a competent individual to refuse treatment that is required to keep that person alive.[78] That refusal may be either contemporaneous[79] or in advance of losing capacity.[80] It also recognises that for a person who has lost capacity, in some cases, continuing to provide treatment is not in that person's 'best interests', although treatment may be necessary to keep him or her alive.[81] In determining a

[76] Cameron L Stewart, 'A defence of the requirement to seek consent to withhold and withdraw futile treatments' (2012) 196 *Medical Journal of Australia* 406. See also Sean Lawrence et al, 'Autonomy versus futility? Barriers to good clinical practice in end-of-life care: a Queensland case' (2012) 196 *Medical Journal of Australia* 404. Skene recognises that s 17(2) of the *Consent to Medical Treatment and Palliative Care Act 1995* (SA) could be interpreted in this way, but also that there are sufficient grounds for courts to interpret the provision consistently with the common law: Loane Skene, 'Withholding and Withdrawing Treatment in South Australia when Patients, Parents or Guardians Insist that Treatment Must Be Continues' (2003) 24 *Adelaide Law Review* 161. Note finally that section 17(2) of the *Consent to Medical Treatment and Palliative Care Act 1995* (SA) will be amended and replaced by Schedule 1, section 11 of the *Advance Care Directives Act 2013* (SA) to put this matter beyond doubt.

[77] Lindy Willmott, Ben White and Jocelyn Downie, 'Withholding and withdrawal of 'futile' life-sustaining treatment: Unilaterial medical decision-making in Australia and New Zealand' (2013) 20 *Journal of Law and Medicine* 907.

[78] *Brightwater Care Group v Rossiter* (2009) 40 WAR 84; *R (On the Application of Burke) v The General Medical Council* [2006] QB 273; *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449; *Re C (Adult: Refusal of Medical Treatment*) [1994] 1 All ER 819; *Airedale NHS Trust v Bland* [1993] AC 789; *Re T (Adult: Refusal of Medical Treatment)* [1992] 4 All ER 649.

[79] *Brightwater Care Group v Rossiter* (2009) 40 WAR 84; *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449; *Re C (Adult: Refusal of Medical Treatment*) [1994] 1 All ER 819.

[80] *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88; *HE v A Hospital NHS Trust* [2003] 2 FLR 408; *Re C* [1994] 1 All ER 819; *Airedale NHS Trust v Bland* [1993] AC 789, 864 (Lord Goff), 892 (Lord Mustill); *Re T (Adult: Refusal of Medical Treatment)* [1992] 4 All ER 649, 653 (Lord Donaldson MR), 662–3 (Lord Donaldson MR), 665–6 (Butler-Sloss P), 669 (Staughton J); *Malette v Shulman* (1990) 67 DLR (4th) 321.

[81] See, for example, the following cases where treatment which was regarded as futile was considered not to be in the patient's best interests: *Melo v Superintendent of Royal Darwin Hospital* (2007) 21

person's best interests, the law will consider the burdens of treatment as well as the benefits.[82]

The second value that the current law promotes, at least in Australia, is the (comparatively) efficient and cost effective framework for resolving disputes that may arise between doctors and family (relevant to value 2.7). Although the Supreme Court in all Australian jurisdictions retains jurisdiction to determine disputes that may arise regarding treatment (and the Family Court can have jurisdiction for disagreements involving children), these disputes are increasingly being decided by tribunals and boards pursuant to guardianship legislation.[83] The guardianship system is expressly designed to resolve matters in a timely, informal and inexpensive fashion.[84]

Despite promoting these two values, the authors contend that there are many important values, articulated in the second section of this article, that are not promoted by the existing law in Australia and New Zealand. The balance of this section critiques the current law with respect to the withholding and withdrawal of potentially life-sustaining treatment against those values. We have grouped the concerns with the current approach into five categories: uncertainty problems that arise from the underdeveloped jurisprudence and lack of legislation in the area; conceptual problems associated with the use of the terms 'futility' and 'necessaries of life'; role problems associated with the roles ascribed to medicine and to doctors; onus problems with respect to invoking dispute resolution processes, and how the law in this field should develop; and the covert nature of the process of allocating health resources.

4.1 Uncertainty, complexity, and inconsistency problems

NTLR 197; *In the matter of Herrington; Re King* [2007] VSC 151; *Messiha v South East Health* [2004] NSWSC 1061; *Airedale NHS Trust v Bland* [1993] AC 789.

[82] See, for example, *Messiha v South East Health* [2004] NSWSC 1061, [22], [23], [28]; *In the matter of Herrington; Re King* [2007] VSC 151, [14]. In the United Kingdom, the courts will balance the benefits and burdens in a balance sheet approach: see, for example, *W v M, S and A NHS Primary Care Trust* [2011] EWHC 2443 (Fam); *NHS Trust v Ms D* [2006] 1 FLR 638.

[83] Australian jurisdictions have statutory regimes that provide for substituted decision-making on behalf of adults who do not have decision-making capacity: *Guardianship and Management of Property Act 1991* (ACT); *Guardianship Act 1987* (NSW); *Adult Guardianship Act* (NT); *Guardianship and Administration Act 2000* (Qld); *Guardianship and Administration Act 1995* (Tas); *Guardianship and Administration Act 1993* (SA); *Guardianship and Administration Act 1986* (Vic); *Guardianship and Administration Act 1990* (WA). These statutory regimes include mechanisms for resolving disputes that can arise. New Zealand has not yet established guardianship tribunals.

[84] Adrian F Ashman and Ron Joachim, 'Consumer satisfaction: Case study from an Australian guardianship jurisdiction' (2010) 18 *Australian Journal of Administrative Law* 20, 20; Victorian Law Reform Commission, *Guardianship Final Report,* Report No 24 (2012) 468; Queensland Law Reform Commission, 'Assisted and substituted decisions: Decision-making by and for people with a decision-making disability', Report 49 (1996), 27. See also note 46 above.

As observed in section 2.4, the rule of law requires that law must be capable of being ascertained. This is not possible when law is uncertain and cannot be confidently stated. Efforts to ascertain the law can be further frustrated where it is complex and inconsistent. The current law suffers from all of these problems.

4.1.1 Uncertainty

In the previous section, we set out some 'general observations' about the law. From even that brief examination of the law, it was clear that it was not possible to provide unequivocal statements because there continues to be some uncertainty with some aspects of the law in this field. The obvious example is that in New Zealand, it is unclear whether family consent is a necessary criterion for good medical practice, and thereby for lawfulness, for withdrawing treatment that doctors consider to be futile. As noted above, the Court of Appeal in *Shortland v Northland Health Ltd*[85] found that fully-informed family consent 'may have been appropriate in the context of the proposed removal of a life-support system'.[86] Obviously, this point is central to the lawfulness of unilateral withholding and withdrawal.

Another example, which was not discussed above, is a more technical legal issue of uncertainty. As we have seen, there is case authority in New Zealand that a doctor may have a legal excuse for not providing treatment, even contrary to family wishes, where such a course represents good medical practice. However, it is not clear whether compliance with good medical practice will be recognised as a lawful excuse in Australian jurisdictions, particularly where the criminal law has been codified. In Code states, it would be unusual to recognise a lawful excuse that does not arise from the terms of the Code or another piece of legislation.[87]

Uncertainty is not surprising given that so much of the law in this area has come from the courts rather than the legislatures. Part of the uncertainty comes from the narrowness of the judicial function which is focused on resolving the particular dispute before the court. This narrowness leads to uncertainty because health care professionals, patients, and sdms do not know what to do when the cases the court has decided are not directly on point to the case they are considering. Justice Munby in *R (on the application of Burke) v The General Medical Council*[88] in the United Kingdom responded to this problem by going well beyond the facts of the case in front of him to try and resolve some of the broader issues relating to decisions about non-treatment. However, he was rebuked by the Court of Appeal for doing so.[89]

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[85] [1998] 1 NZLR 433.
[86] [1998] 1 NZLR 433, 443.
[87] Ben White, Lindy Willmott and John Allen, 'Withholding and Withdrawing Life-Sustaining Treatment: Criminal Responsibility for Established Medical Practice?' (2010) 17 *Journal of Law and Medicine* 849, 862.
[88] [2005] QB 424.
[89] *R (Burke) v General Medical Council* [2006] QB 273, 293.

This aspect of the uncertainty problem does not apply to legislative reform (our preferred approach), as proposed in section 5, where parliament must consider the social, economic, legal and ethical contexts in formulating a legislative response.

4.1.2 Complexity and inconsistency

The statement of the law in section 3 also reveals both complexity and inconsistency. For example, different legal bases have been used for justifying the position that doctors are not obliged to provide treatment that is futile: such treatment is not in a patient's best interests; or criminal liability does not attach because either futile treatment is not a necessary of life, or the non-provision represents good medical practice and is therefore lawful.

Further, in one jurisdiction (Queensland), the law is inconsistent as to when unilateral withholding or withdrawal of treatment may occur. Doctors may unilaterally withhold or withdraw under the common law for adults with capacity and for children, but the guardianship legislation of that State means that consent is required when the decision relates to futile treatment for an adult who lacks capacity.[90]

Such complexities have arisen as a result of the evolution of the common law through the difficult and urgent cases (a famously bad method for making law), as well as through the interaction of the common law with legislation that had not specifically contemplated issues of futile treatment. As noted above, the development of a legislative model (again, our preferred approach) to address this specific issue would avoid these difficulties.

4.2 Conceptual problems

Our concerns about the current legal framework are not limited to the uncertainty, complexity and inconsistency outlined above. Again as noted in section 2.4, the framework is underpinned by concepts about which there is either confusion or disagreement, or which are incompatible with common sense usage of language.

4.2.1 Futility

As we have seen, assessing medical treatment to be futile carries with it significant legal consequences.[91] Yet individuals have different understandings of what is futile treatment, and this has proved to be a barrier to reaching consensus on the meaning of the term. This confusion is also reflected in the terminology used by the judges when determining disputes that arise.

[90] See above at 3.1.
[91] See section 3 above.

The academic literature

There are dozens of definitions that have been promoted in the academic literature from 'simply won't work' (antibiotics simply cannot affect a virus) to not 'worth doing' where 'worth doing' is defined by such measures as varying lengths of survival, levels of quality of life, or likely chance of success of the intervention.[92] Normally we take the position that we should wrestle definitional challenges, posit and defend a definition, and move on. However, here, we do not do so. The definitional fight has been going on for more than 20 years and is still not resolved and we do not think we lose anything important by abandoning that fight. Instead, we think it is important to recognise the distinction between futile(will not work) and futile(not worth doing).[93] In the former case, doctors alone have the expertise regarding whether treatment simply won't work. They should remain the gatekeepers to ensure such treatment is not given to the patient. As there will never be consensus about whether the treatment is futile(not worth doing), we should cease fighting about whether futile treatment means treatment that will not lead to ten minutes survival, sixty days, discharge from hospital, a specific level of quality of life, or a percentage chance of success. Instead, we can more constructively discuss under what, if any, conditions doctors should have the authority to withhold or withdraw treatment without consent or authorization from anyone or anything else, be it patient, family, guardian, court, or tribunal, or without operation of a statute or justifiable government or institutional policy.

Variance in the case law

The inability to agree on the meaning of futility is not limited to academic commentary. In a recent English case, the Court of Appeal expressly acknowledged that judgments about a person's quality of life are implicit in any assessment of

[92] See, for example, Lawrence J Schneiderman, Nancy S Jecker and Albert R Jonsen, 'Medical Futility: Its Meaning and Ethical Implications' (1990) 112(12) *Annals of Internal Medicine* 949; Nancy S Jecker and Lawrence J Schneiderman, 'Medical Futility: The Duty Not to Treat' (1993) 2 *Cambridge Quarterly of Healthcare Ethics* 151; Baruch A Brody and Amir Halevy, 'Is Futility a Futile Concept?' (1995) 20 *Journal of Medicine and Philosophy* 123; Lawrence J Schneiderman, Nancy S Jecker and Albert R Jonsen, 'Medical Futility: Response to Critics' (1996) 125(8) *Annals of Internal Medicine* 669; Raanan Gillon, '"Futility" – Too Ambiguous and Pejorative a Term?' (1997) 23 *Journal of Medical Ethics* 339; Paul R Helft, Mark Siegler and John Lantos, 'The Rise and Fall of Futility Movement' (2000) 343.4 *The New England Journal of Medicine* 293; Deborah L Kasman, 'When is Medical Treatment Futile?' (2004) 19 *Journal of General Internal Medicine* 1053; RK Mohindra, 'Medical futility: a conceptual model' (2007) 33 *Journal of Medical Ethics* 71; S Moratti, 'The development of "medical futility": towards a procedural approach based on the role of the medical profession' (2009) 35 *Journal of Medical Ethics* 369; Ezra Gabbay,et al, 'The Empirical Basis for Determinations of Medical Futility' (2010) 25(10) *J Gen Intern Med* 1083; DJC Wilkinson and J Savulescu, 'Knowing when to stop: futility in the ICU (2011) 24 *Current Opinion in Anaesthesiology* 160; Lawrence J Schneiderman, 'Defining Medical Futility and Improving Medical Care' (2011) 8 *Bioethical Enquiry* 123.

[93] For an analysis of the ethical distinction between 'futile(will not work) treatment' and 'futile(not worth doing) treatment', see Francoise Baylis, 'Expert Testimony by Persons Trained in Ethical Reasoning: The Case of Andrew Sawatzky' (2008) 28 *Journal of Law, Medicine and Ethics* 224.

futility.[94] Sir Alan Ward observed that '[l]ike it or not within the question or perhaps behind it is the ethically controversial question: is it worthwhile keeping this patient alive?'[95] Different definitions of futile, either explicit or inferred, can be drawn from various cases.[96]

It is not surprising that the courts would not be clear on this concept. As noted earlier, it is the subject of extraordinary debate within the academic literature, and there are countless definitions in that literature.[97] But contributing to the confusion is indefensible. This is especially true as the concept of futility is critical in the medico-legal context in that the legal duty to provide treatment currently turns on whether the treatment is futile. As such, it certainly deserves more careful and consistent articulation in the case law.

The inability of lawmakers, here the judiciary, to reach consensus about the scope of this term offends value 2.4 (Rule of law). If it is not possible to determine whether a particular treatment is futile, there will be uncertainty about a doctor's obligation to provide that treatment.

4.2.2 Necessaries of life

The term 'necessaries of life' is a significant one in the legal context. As described earlier, a doctor may have a duty to provide a patient with 'necessaries of life,' and a failure to provide treatment may result in a breach of that duty, potentially exposing the doctor to criminal sanction. Yet 'necessaries of life' seems to have an unspecified scope, with the meaning ascribed to it varying according to the medical context.

We would argue that the meaning of 'necessaries of life' should not be contorted for the law to achieve a result, namely allowing doctors unilaterally not to provide

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[94] *Aintree University Hospitals NHS Foundation Trust v David James* [2013] EWCA Civ 65, [36].
[95] *Aintree University Hospitals NHS Foundation Trust v David James* [2013] EWCA Civ 65, [36].
[96] See, for example, the different formulations in *Re BWV* [2003] VCAT 121, 21 (citing from the judgment of Lord Goff in *Airedale National Health Service Trust v Bland* [1993] AC 789, 869), 24-5, 29; *Messiha v South East Health* [2004] NSWSC 1061, [28]; *Application of Justice Health; re a Patient* [2011] NSWSC 432, [2]; *BAH* [2007] NSWGT 1, [62] citing from the judgment of Howie J in *Messiha v South East Health* [2004] NSWSC 1061, [26].
[97] See, for example, some definitions from the literature listed by Susan B. Rubin, *When Doctors Say No: The Battleground of Medical Futility* (Indiana University Press, 1998), 47: 'Treatments have variously been described as futile if they cannot achieve the goals of: postponing death; prolonging or extending life; improving, maintaining, or restoring quality of life; benefiting the patient; benefiting the patient as a whole; improving prognosis; improving the patient's comfort, well being, or general state of health; reversing or ameliorating an underlying condition; achieving immediate objectives; achieving intended physiologic effects; restoring consciousness; ending dependence on intensive medical care; preventing or curing disease; alleviating suffering; relieving symptoms; restoring function; discharging the patient to home; achieving short or long term survival; achieving the patient's goals; or achieving any of these goals.' See also the literature referred to in note 92 above.

treatment. Our perception is that judges have wanted to be able to say that unilateral withholding or withdrawing treatment is not unlawful, but have run up against the provisions imposing duties to others as a potential barrier to such a result. To circumvent this barrier, 'necessaries of life' has been defined so as to allow the withholding or withdrawal of treatment that doctors (and often doctors *and* family) would agree to. But, in doing the work through the definition of 'necessaries of life', common sense has been left behind. Some have ended up calling treatment that a number of people would want and be supported in wanting, such as ventilatory support, not a 'necessary of life.'

The case law demonstrates the difficulties that this contorted or contrived definition of 'necessaries of life' can lead to. The court in *Auckland Area Health Board v Attorney-General*[98] got tangled up in the concept of 'necessaries of life.' Justice Thomas stated that artificial respiration is a 'necessary of life' if 'required to prevent, cure, or alleviate a disease that endangers the health or life of the patient';[99] and treatment is not a 'necessary of life' if:

- 'the patient is surviving only by virtue of the mechanical means which induces heartbeat and breathing and is beyond recovery';[100]
- it is 'serving no other purpose than deferring certain death';[101] or
- it cannot 'intervene to repel the disease' and '[w]ithout the life-support system death is unavoidable'.[102]

Most worryingly, on Justice Thomas' view of 'necessaries of life,' the following would not be a necessary of life: artificial ventilation supplied to a woman with Guillain-Barre disease or post-polio syndrome who requires the ventilator to live, will not have her disease or syndrome cured by the ventilation, will never recover from her illness, but who wishes to live and, with the help of the ventilator, could live a happy and fulfilling life for ten years.[103]

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[98] [1993] 1 NZLR 235.
[99] [1993] 1 NZLR 235, 249.
[100] [1993] 1 NZLR 235, 249–250.
[101] [1993] 1 NZLR 235, 250.
[102] [1993] 1 NZLR 235, 250. The phrase 'necessaries of life' was also considered by the Queensland Guardianship and Administration Tribunal (as it then was) in *Re RWG* [2000] QGAAT 2. The Tribunal [at 57] relied heavily on the views expressed in *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235 and cited from Thomas J's observation [at 250] that '[i]f ... the patient is surviving only by virtue of mechanical means which induces heartbeat and breathing and is beyond recovery, I do not consider that the provision of a ventilator can properly be construed as a necessary of life'. The Tribunal [at 67] concluded that 'a doctor is under no duty to provide medical treatment which is of no benefit to the patient and would not be in the patients [sic] best interests.' For a general discussion by the Tribunal of 'necessaries of life', see [56]-[67].
[103] Justice Thomas recognized the problem with this distinction in the context of his discussion of 'cause of death' when withholding or withdrawing treatment (*Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235, 248-9). However, he did not recognize it when he discussed

In the context of designing a more coherent model to govern disputes regarding end of life treatment, we would advocate taking a literal approach to necessaries of life – that which is required in order to prevent death. Thus, treatment that will not work is not a 'necessary of life.' It makes no sense to speak of antibiotics for a virus as a 'necessary of life.' They will do nothing for a virus. It makes no sense to speak of cardiopulmonary resuscitation when the patient has 16 bullet holes in her heart as a 'necessary of life.' It simply cannot get the heart restarted.

However, treatment that might work (but might not be worth doing) is a 'necessary of life.' It makes no sense to speak of artificial nutrition and hydration as not a 'necessary of life' where, but for its discontinuation, a patient in a persistent vegetative state might live for five years. It makes no sense to speak of an artificial ventilator as not a 'necessary of life' where, but for its discontinuation, a patient with Guillain-Barre disease might live for ten years. Each of these treatments might not be considered necessary for a life worth living (especially to the patient) but they are clearly necessary for life. And the expression in the criminal law is 'necessaries of life' not 'necessaries of a life longer than 60 days' or 'necessaries of a life of a certain quality', or 'necessaries of life with some other qualitative limitation.'

Whether treatment that might work, i.e., 'necessaries of life,' can lawfully be withheld or withdrawn should be a separate matter that we will come back to later in this paper.

The contorted and contrived interpretation of the term 'necessaries of life' in some cases offends value 2.4 (Rule of law).

4.3 Role problems

This category of concerns relates to the role and purpose of medical science generally, and the influence and power of doctors including a perception that they are the appropriate arbiters of futility. Our concerns are explained below.

4.3.1 Role of medicine

One of the problems with the current legal framework is the role ascribed to medicine: the issues are rendered entirely clinical.

As we have touched on already, a decision about whether or not to provide treatment should involve more than a consideration of clinical issues. Yet, under our current system, the doctors are the decision-makers, a position which suggests

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the term 'necessaries of life' (*Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235, 249-50). See also PDG Skegg "Omissions to provide life-prolonging treatment" (1994) 8 *Otago Law Review* 205 for further critical analysis of Justice Thomas' decision with respect to 'necessaries of life'.

that the decision is indeed a clinical one. Our concern is reflected in comments made by the New Zealand Court of Appeal in *Shortland v. Northland Health Ltd*[104] that 'we cannot see formal ethical consultation as having been necessary in the present case which did not raise significant ethical issues as such. The issues arising were essentially ones of clinical judgment, not ethics.' This is a quite extraordinary statement as this was a case involving a 63 year old man with diabetes, end stage renal failure, and dementia. He was not accepted into the kidney transplant program, and his family was told that dialysis would be discontinued.

Of course, not all decision-makers have failed to see the ethical issues involved and to take them seriously. The coroner in the *Inquest into the death of Paulo Melo*[105] recognised the importance of ethical issues and recommended the formation of an ethics committee to help with similar cases.[106]

The Victorian Civil and Administrative Tribunal in *Re BWV*[107] also recognised that '[the application] raises moral, legal and ethical questions of a profound and fundamental nature, questions literally of life and death ...'.[108] In *Re SAJ,*[109] the Queensland Guardianship and Administration Tribunal (as it then was) heard evidence from an ethicist before providing directions in a contested matter about whether life-sustaining treatment should be continued or withdrawn.

It matters a great deal if the judges reduce everything only to the clinical. If the issues are regarded as entirely clinical, there is more likely to be deference to doctors. If it is recognised that issues are also ethical and philosophical, then there is more likely to be recognition of the limits on doctors' knowledge and expertise, and the conclusion that it is not appropriate to defer entirely to them.[110]

4.3.2 Role of doctors

The earlier point about the role of medicine leads into the next concern we have that, under the current system, the starting point is to accept the doctor's assessment of futility rather than a patient's or sdm's assessment that life-sustaining treatment should be provided. As decisions are not (or should not be thought to be) entirely clinical ones, we argue that this starting point is misguided, and doctors should not hold this privileged position of decision-maker where the treatment would be effective to prolong life and the patient or sdm wants it to be provided.

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[104] [1998] 1 NZLR 433.
[105] [2008] NTMC 080.
[106] [2008] NTMC 080, [110].
[107] [2003] VCAT 121.
[108] [2003] VCAT 121, [4] citing from the judgment of Sir Thomas Bingham MR in *Airedale National Health Service Trust v Bland* [1993] AC 789, 808.
[109] [2007] QGAAT 62.
[110] See further section 4.3.2 below.

The cases also testify to the deference afforded to doctors in this field. The courts in Australia and New Zealand have shown significant deference to doctors.[111] We would argue that this deference has been undue.

Doctors can be wrong when judged by a standard other than the dominant medical model. If they rely solely on the 'gold standard' of the randomised clinical trial, they may discount diagnoses and prognoses based on 'traditional knowledge' and experience in non-dominant cultures. For example, a patient's wife might believe that traditional Chinese remedies might be able to treat her husband's cancer. She might reject the health care team's position that he should have a do not attempt resuscitation order placed on his chart. She might want full treatment for the six weeks that she believes it will take before they can know whether the Chinese remedies will work. It may be appropriate in some circumstances for these alternative bases for decision-making to be determinative.

In addition, doctors are not due deference on moral judgments, and best interests and most futility assessments involve moral as well as medical judgment. Doctors do not have privileged access to values, as contrasted with clinical conclusions or 'medical facts', and what is in a patient's best interests is not merely a matter of their clinical condition. As considered above, whether treatment is 'worth doing' as contrasted with 'won't work' (as is most often the meaning of futility in the cases), depends on value judgments.

This problem can be exacerbated in circumstances of cultural difference between the health care professional and the patient and patient's family. Values can be culture-based and if a health care professional does not understand the patient's culture, he or she may not understand the values at play for the patient. The Victorian case of *Re Herrington,*[112] considered earlier, may be an illustration of this. It will be recalled that Ms King was an Aboriginal woman in a persistent vegetative state. The family did not want antibiotics and artificial nutrition to be withdrawn because of the cultural importance of caring for the unwell. The Court ultimately accepted the views expressed by the doctors and declined to interfere.

Furthermore, some health care professionals have been shown to have biases regarding disability in that they may value the quality of the life of the individual lower than the person living with the disability. The case of Baroness Campbell, considered earlier, is an example of such differing perceptions. Such biases have also attracted judicial attention.[113]

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[111] See, for example, Justice Howie in *Messiha v South East Health* [2004] NSWSC 1061, [25] [relying on O'Keefe J in *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549, [24] as support for this position], [28].

[112] [2007] VSC 151.

[113] See, for example, the Court of Appeal in *R (Burke) v General Medical Council* [2006] QB 273, 303 and Justice O'Keeffe in *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549, [56].

Deference to doctors' judgments about the quality of life, as is inherent in best interests and futility judgments, is therefore undue at best.

The current framework which assigns doctors the role of decision-makers regarding whether or not treatment should be provided offends many of the values articulated in section 2. Respect for a person's autonomy demands that he or she should make decisions about their treatment as they (or their sdm) are in a better position to know what treatment the patient wants or would want. The framework also has the potential to offend the value of humility as it does not require the doctor to defer to the expertise of others in the decision-making process, and a doctor might be tempted to make a treatment decision without considering important, non-clinical factors. As decision-maker, the doctors' conscience is privileged over patients' or their sdm's conscience. Depending on the approach taken by individual doctors, the value of procedural fairness could potentially be compromised. A decision about treatment that is made by a doctor without consultation with the patient or sdm, or a consultation which occurs without comprehensive and effective disclosure of relevant information and treatment options will offend the value of procedural fairness. And a doctor who makes a decision that treatment should not be provided to a person with a disability on the basis of his or her own quality of life assessment, as occurred in the case of Baroness Campbell, offends the value of equality. Finally, access to justice is not maximized (even in Australia where such disputes are generally resolved in guardianship tribunals) as the burden for conflict resolution rests on the patients and their sdms. A system in which the patient or sdm makes the decision would avoid these problems (or potential problems) and promote these critical values.

4.4 Onus problems

This section deals with who should be responsible for certain actions. The first issue concerns who should be required to take action when doctors want to stop (or not provide) treatment but the patient or sdm wants it provided. The second is a broader issue and concerns whether it is the judicial system or parliament that should be responsible for developing the law in this field.

4.4.1 Onus for invoking dispute resolution processes

Under any regulatory model, disagreements about treatment will occur at times between the health care team and the patient or, more likely, the patient's family as sdm. It is important to have dispute resolution procedures that are fair, accessible and efficient. For the most part, guardianship tribunals and boards satisfy the need for accessibility and efficiency. There is, however, room for improvement. As the law now stands, there is generally no requirement for doctors to provide treatment

they assess to be futile and the onus is on the patient or family to make the necessary steps to challenge that decision.[114]

We can identify four reasons why the burden of challenging a doctor's futility assessment should not rest with the patient or sdm but rather, the onus should be on the doctor or institution to bring the action.[115] Firstly, the family will not necessarily even know that the doctor has decided to withhold or withdraw treatment, so will not know to initiate a process to challenge that decision. This is particularly so in relation to decisions to *withhold* treatment as the family may well be unaware of the possibility of receiving the treatment that was considered but not offered. Secondly, even if they are aware that a decision to withhold or withdraw has been made, they would not necessarily know that they can challenge the decision in a legal forum. Thirdly, there is a power imbalance, and they may not feel empowered to instigate such a challenge (and possibly may feel that their loved one will not get good care if they make such a challenge). Fourthly, it may cost the family more to launch the action than to defend against it, and the family will usually have less financial resources at their disposal than the doctor or institution.

Under the current model of regulation, the onus is on the family to bring the action if they disagree with the doctor. The values of procedural fairness, access to justice, and perhaps even humility require that the view of the family is followed or, if the doctor is not prepared to provide the treatment on futility(not worth doing) grounds, the onus is on the doctor or institution to bring the action.

It is important to note here that we are not arguing against doctors and institutions having access to a dispute resolution process. There will be times when a patient's sdm will not be acting in accordance with the patient's best interests or according to what the patient would have wanted. There can, of course, be financial and other conflicts of interest operating and sdms can also be mistaken about a patient's prior wishes or best interests. Doctors and institutions should have an avenue to challenge improper or mistaken decisions taken by patients' sdms. Our point here is simply that they, rather than the patients' sdms should bear the onus for invoking the dispute resolution process.

4.4.2 Onus for making law through courts instead of legislatures

Unilateral withholding and withdrawal cases frequently come to the courts at a time of crisis. The case of *Messiha v South East Health*[116] is a good example. The patient

[114] Note, however, that a doctor in Queensland may need authorization to withhold or withdraw treatment if the sdm is refusing to consent to its withholding or withdrawal. See further 3.1 above.
[115] The suggested approach has also received judicial endorsement: *Re T (Adult: refusal of medical treatment)* [1992] 4 All ER 649, 663; *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449, 474, 475.
[116] [2004] NSWSC 1061. For further case examples of decisions that were made in a time-pressured context, see *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549, *Melo v*

was a 75 year old man who suffered a cardiac arrest and his brain was deprived of oxygen for at least 25 minutes. He was unconscious and apparently in a deep coma, and was admitted to the intensive care unit. He was being artificially ventilated and receiving artificial hydration and nutrition. The health care team believed that no further treatment would be in the patient's best interests and wanted to stop aggressive treatment. Without such treatment, the patient would surely die. The family disagreed with the decision and wanted the court to issue an injunction to compel the health care professionals to continue this treatment. The patient was at significant risk if the doctors proceeded to withdraw the treatment. Obviously, the decision needed to be made quickly.

Yet making law (as opposed to merely applying settled law) in crisis mode does not allow adequate time for the lawyers involved to carefully research and develop their arguments.[117] In addition, the novel or rare nature of these applications generally means that there is not a large number of experienced lawyers to be involved. How many of the lawyers involved in the various cases in Australia and New Zealand had ever argued a futility case before? How many even knew about the debate in the bioethics literature let alone had read the many papers written on this topic since the 1980s? How many could get meaningfully up to speed on the issues in 12 or 24 hours?

Similarly, making law (again, as opposed to merely applying it) in crisis mode does not allow adequate time for judges to work through the legal arguments and prepare carefully drafted reasons. Despite the growing numbers of these kinds of cases arising in Australia and New Zealand, there is no equivalent of *Airedale NHS Trust v Bland*,[118] a case in which the relevant legal arguments have been fully explored and jurisprudence developed in detailed, lengthy and considered judgments. The limited capacity to develop the law in a carefully considered way has been judicially recognised.[119] The uncertainty, inconsistency, and conceptual problems with the law, as identified earlier, demonstrate this point.

Finally, there is a human cost to developing law through individual cases. Making law on the backs of individuals who are very ill and their families who are going through such difficult times and health care professionals who are trying to do what they think is best puts a huge burden on all of them. It is one thing to have to go to court as a place of last resort where the court needs only to review evidence put before it to resolve conflict over what should be done for a particular patient in the

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Superintendent of Royal Darwin Hospital [2007] NTSC 71, *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235; *State of Queensland v Astill* (Unreported decision, Supreme Court of Queensland, Muir J, 18 January 2006).

[117] Indeed, in *Slaveski v Austin Health* [2010] VSC 493, a man acted on his own behalf in a Supreme Court application to prevent Austin Health from withdrawing life-sustaining treatment from his father, and the Court commented on the difficulty in obtaining relevant material in such circumstances: [3]. He obtained legal representation later in the application.

[118] [1993] AC 789.

[119] See Thomas J in *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235, 243.

face of irreconcilable conflict between the health care team and the patient's family.[120] It is quite another to have to go to court and spend time arguing over what the law is and requires and then over how to apply the law to the facts of the case.[121] Yet this is precisely what is required given the failure of the legislatures to act.

The possibility of a comprehensive solution to this problem and the opportunity to advance the rule of law through enhanced certainty both point to legislation as the appropriate vehicle through which reform should occur. So too does the value of access to justice.

4.5 Covert allocation of health resources

For the most part, the law asks doctors to make individual treatment decisions based on a patient's best interests without considering resource allocation issues.[122] However, we know that that is not what happens. Doctors in charge of departments with limited beds (e.g., intensive care units) make resource allocation decisions. Sometimes these decisions are dressed up as decisions grounded in conclusions about the futile nature of the treatment, with a denial that there is any rationing going on. However, except where the treatment is not able to help a patient (ie treatment is futile because it 'will not work'), there may be a resource allocation component to the decision. The problem is that our current system of regulation has not yet properly addressed the intersection of the specific issue of treatment of individual patients and the broader systemic issue of the allocation of scare health resources.

The current system which does not separate the issue of allocation of health resources from decisions about treatment in individual cases offends the value of distributive justice. The system fails to ensure that health resources are distributed in a fair way. And if we accept that resourcing decisions are being made by doctors and those decisions affect patient treatment, the system also offends the value of procedural fairness and transparency in decision-making.

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[120] Examples of this kind of conflict can be found in *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549; *Messiha v South East Health* [2004] NSWSC 1061; *Melo v Superintendent of Royal Darwin Hospital* [2007] NTSC 71.

[121] Examples of end of life cases where clarification was needed include *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235; *Re G* [1997] 2 NZLR 201; *State of Queensland v Astill* (Unreported decision, Supreme Court of Queensland, Muir J, 18 January 2006); *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88; *Brightwater Care Group v Rossiter* (2009) 40 WAR 84.

[122] *Messiha v South East Health* [2004] NSWSC 1061; *Melo v Superintendent of Royal Darwin Hospital* [2007] NTSC 71, [9]. Note, however, that the situation might be different where a decision not to provide treatment is based on guidelines specifically developed to ration finite resources such as for organ transplantation or access to dialysis programs. In *Shortland v Northland Health Ltd,* a case about a patient's access to dialysis, both the High Court (unreported, 6 November 1997, Salmon J) and the Court of Appeal ([1998] 1 NZLR 433, 443) indicated that resource constraints could be a relevant factor when decisions are made about treatment.

5. A Proposed Model

From the paper so far, it will be clear that we favour a change to the law: a doctor should not be able to withhold or withdraw unilaterally on the basis of her or his opinion that treatment is 'futile', not in the 'best interests' of the patient or is not 'good medical practice' or 'appropriate medical treatment'. And while the broad principles of our proposed approach have been flagged in the discussion to this point, in this section, we draw together these principles and articulate the elements of our proposed model.

A preliminary point to be made here is that we propose reform should occur by way of statute. This would avoid the deficiencies outlined above which arise when law is developed through the courts. A comprehensive legislative model is preferable from both rule of law and access to justice perspectives. Courts and tribunals would continue to have a role in resolving disputes about what should be done in the face of conflict in particular cases but they should be being asked to apply rather than make the law.

5.1 A shift of decision-making power

At the heart of our model is a shift of decision-making power from doctors to the patient and his or her sdm. This authority to decide is qualified (as will be seen below) and can be challenged but it represents a starting point as to who has the authority to make a decision about treatment or non-treatment. Such an approach better gives effect to the values of life and autonomy; that decisions about medical treatment begin with the patient, particularly where the proposed decision is to stop treatment leading to his or her death. This model also better advances the value of equality as it imposes a barrier to doctors inappropriately determining a life is not worthwhile based on considerations such as age or disability.

Our approach establishes a legal process that promotes the values of procedural fairness, access to justice and humility. By locating the decision-making power with the patient and sdm, a doctor and the health system need to engage with them in making decisions and a doctor is prevented from unilaterally deciding to stop or not start treatment. Entrenching this process in the law requires the provision of information, discussion with a patient about possible treatment options and transparent decision-making (procedural fairness). It places the burden of challenging a decision about the provision of treatment on those who can best carry it, namely the doctors and the health system (access to justice). And it embeds in the decision-making process appropriate recognition and a role for non-clinical values, and limits the role of medicine and doctors accordingly (humility).

5.2 Provide requested treatment that can work except if lawful excuse

It is beyond the scope of this article to provide the details and mechanics of how statutory reform should be effected, but we outline the principles, given the core values discussed earlier, that we argue should operate.

5.2.1 A duty to provide the necessaries of life

The starting point is that doctors should continue to have an obligation to provide patients with the necessaries of life, and patients should be able to request treatment that fits within this definition. As noted earlier in this article, we reject the more qualitative approach of Thomas J in *Auckland Area Health Board v Attorney General,*[123] and instead recommend that this term be defined in a common sense, factual manner to mean simply treatment that is necessary to sustain life. If treatment is capable of sustaining life, it will be a necessary of life regardless of whether you, I or the doctor might think it is not worth doing. This avoids sophistry and the lawfulness of a non-treatment decision turning on subjective judgments of doctors (and so advances the value of the rule of law).

This also means that there will be a duty to provide a wider range of treatments than presently is the case, but, it should be emphasised, there will not be a duty to provide *all* treatment. The concept of treatment that 'will not work', such as antibiotics for a virus, was discussed above and such treatment will not be a necessary of life - it is not capable of sustaining life. This means there will be no duty to provide such treatment and a patient or sdm will not be able to lawfully require it to be given.

5.2.2 A lawful excuse not to treat

But what of the remaining treatment that would constitute a necessary of life? Can a patient or sdm always request such treatment and must a doctor always provide it? We recommend that the circumstances in which a doctor is *not* obliged to provide necessaries of life be clearly articulated. These circumstances would provide the doctor with a 'lawful excuse' for not providing treatment. We set out these circumstances below.

<u>Receiving consent to withhold or withdraw treatment, or other authorization</u>

A doctor should be excused for not providing treatment if, after consultation with the patient or legally authorised sdm, including any statutory officer who has such

[123] [1993] 1 NZLR 235, 249.

authority,[124] consent is given to withhold or withdraw the treatment. This excuse should also extend to consent contained in a valid advance directive, or to a court order or tribunal decision. This also reflects the shift outlined above to patients and sdms as the decision-maker.

Existence of a valid statutory regime or government or institutional resource allocation policy

Earlier in the paper we recognised that there are limits to when treatment can be provided. Recognising such limits is consistent with the value of distributive justice. Rationing of health care is inevitable and ethically appropriate.[125] However, we have argued it must be done overtly, not covertly, and it needs to happen through a process that reflects the value of procedural fairness.

Rationing may need to occur both at a governmental level through enactment of legislation or development of departmental policies. It may also occur at the institutional level through hospitals developing policies that are specifically tailored to their own circumstances. This will no doubt be challenging. Broad and meaningful consultation is necessary, as is ensuring that the composition of any drafting team is representative of stakeholders, particularly those who are likely to be adversely affected by such policies. Yet such an exercise is critical to develop a reasoned, coherent, ethical and just response to this vexed issue.

Regardless of the mechanism used, the statutes and policies need to be developed according to administrative law principles and human rights norms and must be consistent with the values we have identified above. Doctors should be excused for not providing treatment pursuant to such legislation or policies.

Physical impossibility

There may be some situations in which treatment is a physical impossibility. For example, there may be no dialysis machine or oncology services in the town in which the patient lives or can travel to. A doctor should not be liable for not providing the necessaries of life where it is not physically possible to do so. It is likely that such conduct would not be unlawful in any event, even without an excuse, as civil or criminal liability is, as a rule, not imposed for failing to do something which is impossible. Nevertheless, for the sake of clarity and completeness, this should still be specifically included in the legislative scheme as providing a lawful excuse for non-treatment.

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[124] In Queensland, the Office of Adult Guardian is the default decision-maker if the adult does not have friends or relatives who are readily available and culturally appropriate: *Powers of Attorney Act 1998* (Qld), s 63(2). For a consideration of other circumstances in which a statutory officer may be involved in the decision-making process, see generally Ben White, Lindy Willmott and Shih-Ning Then, 'Adults Who Lack Capacity: Substitute Decision-Making' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson Reuters, 2010) 150.

[125] George P Smith II, *Distributive Justice and the New Medicine* (Edward Elgar Publishing, 2008) 17.

Transfer of the patient to a doctor who will provide the desired treatment

The value of enabling a doctor to act in accordance with his or her conscience was recognised earlier. A doctor should not be required to provide treatment to a patient if treatment is contrary to his or her conscience, if it is possible to transfer the patient to a doctor willing and able to provide that treatment. However, if transfer is not possible, treatment should continue until there is some other lawful excuse not to treat.

5.3 Likely impact of the model

We anticipate that there are at least two likely impacts of the proposed model, both of which will have advantages and disadvantages. The first is that it is likely to result in more communication between doctors and patients and their sdms, leading to greater transparency in decision-making. For example, under our model, where a patient/sdm is asking for treatment that simply will not work, doctors should explain this to the patient/sdm and indicate that they will not provide it. Where potentially life-sustaining treatment exists, but is physically impossible to provide, again they should explain this to the patient/sdm. Where there is potentially life-sustaining treatment but provision is precluded by a valid resource allocation policy, they should again explain this to the patient/sdm. But where there is no lawful excuse for non-treatment, the doctor should offer the various treatment options to the patient/sdm, along with his or her professional advice as to the appropriateness of various courses of action. Under the current law, which permits unilateral medical decision-making, some of these discussions can be avoided. But a shift in the starting point for how these decisions are made will promote greater engagement by doctors with patients and their sdms.

A disadvantage of this first impact is that communication like this will take more time, and time is a precious commodity in medical practice. However, we would also argue that it is an advantage of a legal framework to formalise and promote good communication. Further, ethical principles of good medical practice already require patient/sdm participation and consultation in decision-making[126] so the sorts of discussions mentioned above should already be happening to some extent.

A second likely impact we can foresee is that increased information sharing and a shift in decision-making authority may lead to a small increase in the number of cases requiring dispute resolution. Under our model, if a conflict arising from a

[126] See, for example, Medical Board of Australia, *Good Medical Practice: A Code of Conduct for Doctors in Australia,* in particular sections 3.3.1, 3.12.1 and 3.12.7, <http://www.medicalboard.gov.au/Codes-Guidelines-Policies.aspx>, and Medical Council of New Zealand, *Good Medical Practice: A Guide for Doctors,* sections 11 and 17, <http://www.mcnz.org.nz/assets/News-and-Publications/good-medical-practice.pdf>.

patient or sdm request for treatment cannot be resolved, the doctor should either transfer the patient to another doctor willing and able to provide the treatment or, if that is not possible (and there is no other lawful excuse available), continue to treat and seek authorization to withhold or withdraw treatment from a court or a tribunal. The vast majority of disputes that currently occur are resolved by effective communication.[127] There is no evidence to suggest that this would not continue to be the case under our model. We would argue that concerns about the floodgates opening and a large volume of disputes arising are misplaced.

That said, it is likely that the number of disputes occurring will be more than at present where doctors can make decisions not to offer treatment which patients/sdms never know about, or make decisions that patients/sdms lack the resources and ability to challenge through a formal dispute resolution process. But this begs another question – are those decisions ones that should be allowed to be made without the possibility of a dispute being raised, discussed, and resolved through more formal means?

To say that more disputes requiring resolution is a bad thing in and of itself presumes that the decision-making which is not presently being contested is appropriate. We argue, for reasons outlined earlier, that this is not the case. Indeed, the model we have designed, which draws on principles such as transparency and information sharing promoted by procedural fairness and other values, will improve the quality of decision-making. Our view is that if there is a small increase in the number of cases that need dispute resolution, that cannot be said to be a bad thing. If, after extensive communication, a dispute remains where a patient or sdm has a different view from a doctor as to whether life-sustaining treatment should be provided, then we would argue that such a dispute is one that should be tested and resolved through an appropriate mechanism. Given a person's life is at stake, a fair and transparent process to decide whether he or she should receive treatment is a reasonable response from the law.

6. Conclusion

In section 2 of this article, we identified and explained the values (and the balancing of values) that we argued should ground the legal framework in this area. Those values were: life, autonomy, equality, the rule of law, distributive justice, fairness, access to justice, conscience and humility. We then, in section 3, gave a brief overview of the law in this area which generally concluded that doctors are granted significant powers to make decisions to withhold or withdraw potentially life-sustaining treatment unilaterally. This law was then critiqued in section 4 against the values earlier outlined. We identified problems of: uncertainty, complexity, and inconsistency in this area; that key legal concepts are unclear or understood in ways

[127] New South Wales, CRELS Project Working Group, *Conflict Resolution in End of Life Settings (CRELS) Final Report* (2010) 5.

that are incompatible with common sense usage of language; that the law permits overreach with respect to the role of both medicine and doctors with respect to decision-making in this area; that the design of the law imposes burdens on those who should not have to carry them; and that the current law permits covert rationing.

The model that we proposed in section 5, based upon a shift from doctors to patients and sdms as decision-makers, addresses our concerns about the current legal framework. We anticipate that some, perhaps many, will not endorse the suggested approach. Nevertheless, we advocate this model to further the important values that should underpin a legal framework when making decisions about life and death. We also predict that the cultural shift this model requires is perhaps not as great as may be imagined at first glance, particularly for doctors who currently engage patients and families in a genuine, meaningful and respectful way in discussions about treatment at the end of life. Our hope is that the adoption of this model will improve outcomes for all, particularly better care for those who are dying and their families.